History of the Organ Donor Register

The NHS Organ Donor Register is, quite literally, a lifesaver. The confidential, computerised database records the wishes of people who have decided that, after their death, they want to leave a legacy of life for others. By 1 January 2011, the NHS Organ Donor Register contained the names of more than 17.7 million people.

Launched in 1994 following a five-year campaign by a donor family, the register is operated and maintained by the Organ Donation and Transplantation Directorate, part of the special health authority NHS Blood and Transplant. John Cox, a retired civil engineer, and his wife Rosemary saw the need for an official record of a person’s wishes to be an organ donor after their 24-year-old son Peter died in 1989, following a brain tumour.

Peter had asked before his death for his organs to be used to help others, but his parents found that although patients in need of a transplant were listed on a central NHS computer, there was no equivalent register for potential donors. The West Midlands couple, with the help of their daughter Christine, began their campaign. The breakthrough came when Christine made an impassioned plea from the rostrum for a register of donors’ wishes, during a health debate at the Conservative party conference at Blackpool in 1993. Health Secretary Virginia Bottomley, who was at the conference, pledged there and then to set up an NHS Organ Donor Register (ODR).

Tom Sackville, then the Health Minister for transplantation, immediately began putting the plan into action and, after a whirlwind of consultation and co-ordination, the new register was launched on 6 October 1994. Launching the scheme, Mr Sackville, MP for Bolton West, heralded the database as a landmark in the development of organ donation and transplantation in the UK.

The register contains the surname, forenames, date of birth, sex and address of the potential donor. People can opt for any part of their body to be transplanted or for specific organs only – kidneys, heart, lungs, liver, pancreas and eyes. Individual records are matched with NHS numbers to ensure that registrations are not duplicated. Details are amended or removed as required. There is no upper or lower age limit to joining.

An advertising campaign persuading people to join the new register was launched the following year. Seventy-eight thousand balloons, symbolising the number of transplants and donors recorded in the UK and Ireland since 1972, were released from Crystal Palace. Advertisements were placed in national and local newspapers and leaflets explaining the scheme were delivered to more than 19 million households.

A key element to the success of the register was the decision to enable people to let their wishes be known through an organ donation tick box on driving licence applications. Another route to the register opened in April 1995 enabling people to join when they register with a GP.

By the end of 1995, more than 2,330,000 people had joined the register. That figure had soared to 8,440,000 by the end of 1999 and in January 2005 the number of people who had made a life-giving
decision passed 12,000,000. By January 2009, the total had reached the 16,000,000 target set by the Government in 2001, a year ahead of schedule.

The Driver and Vehicle Licensing Agency (DVLA) and GP registration forms remain the two most popular methods of joining the register. The DVLA scheme alone has been used by nearly eight million people to make their wishes known. Holidaymakers are able to sign on with leaflets sent out to applicants for UK passports and the new European Health Insurance Card (EHIC), and Boots includes a tick box for people to join the register on its Advantage loyalty card application form. Dozens of UK charities also work tirelessly to raise awareness of organ donation and transplantation.

The 10th anniversary of the ODR was marked by a year-long challenge to the nation, from 6 October 2004 to 5 October 2005, to add one million more “lifesavers” to the register during this period. The government has now set a target of increasing the number of people on the register to 25 million by 2013.

In November 2009, multi-media organ donation campaign “Prove it!” was launched. The campaign aimed to convert people’s good intentions about organ donation into action by registering on the NHS Organ Donor Register. Road shows were held in 20 locations across England, Northern Ireland and Wales. Within the first few months of the campaign more than half a million new people joined the register, taking the total to over 17 million and representing a rise from 27 per cent of the population to 28 per cent.

With the introduction of the Human Tissue Acts on 1 September 2006, which give precedence to the wishes of the donor, it is hoped that more families will be encouraged to respect their loved one’s wishes. It is important that you discuss organ and tissue donation with the people closest to you so that, if the time ever comes, they will find it easier to confirm your wishes to NHS professionals.

You can find out more about organ donation and join the NHS Organ Donor Register by calling 0300 123 23 23 or visiting the NHSBT website www.organdonation.nhs.uk

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